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I am who I am through who we are: The potential role of *ubuntu* in neurorehabilitation

Soy quien soy a través de quienes somos: El papel potencial de ubuntu en neurorehabilitación

Sou quem sou através de quem somos: O papel potencial de ubuntu em neuro-reabilitação

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Abstract

This paper explores the African concept of *ubuntu*, and its potential to influence our thinking about the delivery of long-term health and social care within a neurorehabilitation context. Particular consideration is given to the potential importance of achieving longer-term social connectedness for clients and their relatives after neuro-rehabilitation interventions have finished. A short case vignette, and a hospital-based practice report, are provided as two examples to illustrate some of the key points made. Incorporating some aspects of the philosophy of *ubuntu* could potentially help neurorehabilitation programmes to include the reduction social disability as a more explicit longer-term goal for outcome.

Keywords: Ubuntu; neurorehabilitation; practice report

Resumen

Este documento explora el concepto africano de Ubuntu y su potencial para influir en nuestra forma de pensar sobre la prestación de asistencia sanitaria y social a largo plazo dentro de un contexto de neuro-rehabilitación. Se presta especial atención a la potencial importancia de lograr una conexión social a largo plazo para los clientes y sus familiares después de que las intervenciones de neuro-rehabilitación hayan finalizado. Se proporcionan una pequeña viñeta de caso y un informe de práctica práctica hospitalaria, como dos ejemplos para ilustrar algunos de los puntos clave al respecto. Además, los autores incorporan algunos aspectos de la filosofía de Ubuntu que podrían ayudar a los programas de neuro-rehabilitación que podrían influir en la reducción de la discapacidad social como un objetivo más explícito a largo plazo para el resultado.

Palabras clave: Ubuntu; neurorehabilitación: practica hospitalaria.

Resumo

Este documento explora o conceito africano de Ubuntu e seu potencial para influenciar na nossa forma de pensar sobre a prestação da assistência sanitária e social a longo prazo dentro de um contexto de neuro-reabilitação. Se presta especial atenção à potencial importância de conseguir uma conexão social a longo prazo para os clientes e seus familiares depois de que as intervenções de neuro-reabilitação estiverem finalizadas. Se proporciona uma pequena vinheta do caso e um informe de prática hospitalar, como dois exemplos para ilustrar alguns dos pontos chave a esse respeito. Ademais, os autores incorporam alguns aspectos da filosofia de Ubuntu que poderiam ajudar nos programas de neuro-reabilitação que poderiam influenciar na redução da incapacidade social como um objetivo mais explícito a longo prazo para o resultado.

Palavras-chave: Ubuntu; neuro-reabilitação: prática hospitalar;

‘My humanity is caught up, is inextricably bound up, in yours.’ (Archbishop Desmond Tutu)

Introduction

‘If I could have my life over, would I choose not to have had a brain injury? No, I don’t think so. I would have everything the same.’ This was a spontaneous reflection by a client during a psychotherapy session, about having suffered a severe traumatic brain injury several years earlier. The client was attending a long-term psychotherapy and review follow-up appointment with the first author (RC) of this paper. A protracted period of silence followed the client’s comment. Being genuinely surprised, the therapist asked the client why this might be the case. The client answered by saying that had he not sustained his brain injury, he would not have met the people with whom he was now doing voluntary work, nor would he have gained his sense of altruism, purpose and of making a contribution to others’ lives in the community. The client thought this very much defined a core aspect of his identity as part of his ‘new life’ after brain injury. Undoubtedly, the above narrative reflects an extraordinary therapy-based interaction by any measure - more information regarding this client’s clinical history and the management of his case follows a bit later in this paper.

In most situations acquired brain injuries such as stroke or traumatic brain injury result in physical, cognitive, emotional and behavioural difficulties, which in turn are associated with ongoing disability. Besides the obvious disability at the individual and personal level, clients’ wider systems, including their families, ultimately their communities, and society, are also adversely affected. As a result, in many cases their interconnectedness to others is lost. Generally viewed, the broad generic aim of neurorehabilitation is an attempt to reduce the impact of clients’ impairment and associated disability. However, ‘rehabilitation’ means different things to different people. Rehabilitation may include medical-, psychological-, social-, occupational- or functional rehabilitation, among others. The different emphases placed on the process of rehabilitation often reflect a normal variation in practice of the range of professionals working in the area, rather than major philosophical, theoretical and practical differences in approaches. To some extent rehabilitation may appear unidirectional in the sense that ‘stuff is done to and for the client’, but what about the potential for clients and the broader systems to ultimately interact in a more bidirectional, interconnected way with the process of rehabilitation?

Inevitably, ideas and models of rehabilitation, even when framed as clinical-scientific developments are influenced, at least in part, by the assumptions and world-views of the host culture. These include social constructions of personhood linked to healthy and damaged brains. In the Western world, generally a construction of the autonomous individual permeates. Following brain injury, rehabilitation goals are commonly coloured by this discourse. Accordingly, interdisciplinary clinical teams set to work supporting the survivor of brain injury, to return to independence as a priority, both in terms of their functional activities and their own management of mind and emotions. While congruent with many of the ideals of client-centred care, some important limitation starts to become apparent when taking a broader, societal view on the endeavour that constitutes brain injury rehabilitation. To some extent, this results from an almost exclusive focus on the individual as the ‘index patient’.

Firstly, the ubiquitous and widespread strain, and often devastation of relationships that it is a common consequence of a neurological condition, does not frequently feature as co-rehabilitation business. This being the case, despite the psychological distress that occurs for both the survivor and their significant others. The experiences and needs of the latter frequently are not seen, or responded, to within survivor-focused rehabilitation services. Social isolation is one of the major adverse outcomes many people face after an acquired brain injury. Indeed, clients who attend rehabilitation very often report social isolation as one of their main problems, leading to other difficulties such as for example depression. Secondly, the experience of the therapist (counter-transference) in interaction with the survivor is minimised, even if this includes challenges and forms of distress for the clinician. Often these reactions are seen as obstacles to the core business of rehabilitating the client, and not as an informative window on the intersubjective space-between or a key domain through which a neuro-anatomical lesion manifests itself (Kaplan-Solms & Solms, 2000; Lewis, 1999). Counter-transference is integral to many psychotherapeutic approaches, including therapeutic work with persons who have suffered a neurological injury or illness.

There is now fairly robust evidence that cognitive and holistic neuropsychological rehabilitation following brain injury can have beneficial effects on a range of outcomes (Caracuel, Cuberos-Urbano, Santiago-Ramajo et al., 2012; Cicerone, Langenbahn, Braden et al., 2011; Cicerone, Mott, Azulay et al., 2008; Powell, Heslin & Greenwood, 2002). Furthermore, Stalder-Lüthy et al. (2013) reported in a recent review that psychological interventions could have a positive outcome on depression associated with acquired brain injury. Naturally, many rehabilitation interventions have increased participation in occupational-, community-, and educational activities (among others) as a primary goal, and as a desirable outcome to work towards as part of the rehabilitation process. In reflecting on the dilemmas associated with focusing too exclusively on achieving participation at, or near to, pre-morbid levels as a desired outcome in brain injury rehabilitation programmes, Cicerone (2013) suggests that neurorehabilitation research should aim to achieve an optimal balance between rigor and relevance. For example, a technically successful rehabilitation intervention for memory compensatory strategies may not necessarily always translate into clients' reconnecting with others, or into deriving a sense of recapturing purpose in their lives. Clients and their families' rehabilitation goals may differ from those of professionals.

In contrast to the aforementioned framing of rehabilitation goals and practices by individualist cultural values, a rehabilitation focus on relationships (Bowen, Yeates & Palmer, 2010), on supporting inter-dependence (Yeates et al., 2013) and rebuilding the strained connections between people has been sporadically articulated but remains an exception. This is despite the demonstration of psychological benefits for both survivors of brain injury and their relatives following relationship – focused rehabilitation (see Bowen, Yeates & Palmer, 2010 for review), and the known value of enhanced community and group roles for post-injury adjustment. Williams, Rapport, Millis and Hanks (2014) reported findings from their study suggesting that satisfaction with life after traumatic brain injury was positively associated with peoples' community involvement and inversely to their emotional distress. Haslam and colleagues (2008) have empirically demonstrated the significance of both pre-injury social group membership and the post-injury assumption of new social and leisure groups for stroke survivors.

The notable exceptions of relationship-focused rehabilitation are encouraging. For example, a UK community neurorehabilitation team was established with family and couples support as a core pillar of its model of service delivery (Tyerman & Booth, 1991; Yeates et al., 2013). Furthermore, Gerber and Gagaro (2015) describe findings from a programme that increased community participation, and as a result improved reintegration into society, as well as reduced the burden of relatives. These authors posited that community-based programmes could be very useful after time-limited formal rehabilitation has ended in helping survivors and their families engage in meaningful activities (Gerber & Gagaro, 2015). In addition, the findings of Martin, Levack and Sinnott (2015) suggest that brain-injury rehabilitation interventions should have a particular focus on achieving social connectedness. In essence, as opposed to a more individualistic focus, some of these studies suggest that the broader societal outcomes of neurorehabilitation interventions can potentially benefit from a more collectivistic approach.

Case vignette

Let us now return to the client's narrative contained in the first paragraph of this paper. This client, Mr M, has been reported in much greater depth elsewhere (Coetzer, 2010). In summary, Mr M, an engineer, was in his early sixties when he sustained multiple injuries, including a severe traumatic brain injury with right-sided subdural hematoma and haemorrhage following a road traffic collision. Mr M spent a considerable amount of time in both acute and community hospital settings, requiring further surgery, rehabilitation and convalescence prior to his discharge home. His physical impairments rendered him unable to return to employment. Mr M was referred for community-based brain injury rehabilitation approximately one year after sustaining his brain injury. At that time Mr M presented with profound physical impairment, cognitive difficulties (information processing and memory), and low mood characterised by loss of purpose, feelings of guilt, worthlessness and shame. However, there were none of the somatic markers associated with clinical depression present, such as for example insomnia and loss of appetite.

Mr M was seen for psychotherapy follow-up as part of his ongoing brain-injury rehabilitation. In particular, the psychotherapy provided was intended to help him with his depressed mood and reported loss of purpose in life. One of the main themes to transpire during psychotherapy related to his changed role and identity within social relations, his marriage as well as engaging with the wider community. Mr M thought that it was very difficult to find new meaning and purpose in his life due to the injury that he sustained and its associated disability, and also because of his age. Psychotherapy focussed on defining new purpose and meaning by working collaboratively with him to define personally meaningful goals, and encouraging engagement with personally salient activities. As a result, Mr M gradually started to participate in voluntary work within the community. This entailed working on a weekly basis with disadvantaged youths. He eventually reported finding new purpose in life and an associated improvement in his low mood. After several months, he was put on six-monthly review, and it was during one of these follow-ups appointments that the narrative in the introductory paragraph of this paper transpired. Through his voluntary work with others **'less fortunate than me', Mr M felt a sense of meaning, altruism, making a contribution to society and being reconnected to the community.**

On reflection, one of the observations from this case vignette was that, over time, psychotherapy themes gradually progressed from more intrapersonal themes, such as what was lost as a result of the injury, to more inter-personal themes (for example social isolation) and to a narrative of what might still be possible to contribute to others' lives. Therapist activities and counter-transference reflected this process to some degree. During the initial stages there was an acute awareness of the client's pain, low mood and sense of loss, but over the course of many sessions this was gradually replaced by a sense of hope – what might still be possible – in the context of the absence of a 'cure' to remove terrible symptoms. As such, during the early stages of therapy perhaps the subconscious therapeutic approach was trying to help the client with the 'removal' of symptoms of distress, impairments and obstacles, whereas later stages had a much stronger focus on adding, reconnecting and finding purpose, thus reducing disability.

Ubuntu and healthcare

How we deliver health and social care in society, is influenced by many factors. For example, Cicerone (2012) emphasised that, in addition to the science, we also need to consider the *values* underpinning brain-injury rehabilitation. Clinicians often consciously (or subconsciously) view rehabilitation as something that is provided to clients in order to reduce their impairments and the associated disability. What is successful in the clinic may not always transfer to persons' post-rehabilitation lives to be lived in communities. For example, clients and their families' sense of belonging, or purpose and connectedness, are rarely, if ever, explicit rehabilitation goals. Perhaps one avenue to explore this post-

rehabilitation stage is to consider the cultural concept of *ubuntu*, which may inform rehabilitation professionals' thinking about longer-term societal outcomes after rehabilitation also. *Ubuntu*, put very simplistically, is humanism within the context of Africa. It is an African philosophy, culture or set of values whereby the wellbeing of the group is deemed more important than that of the individual. In essence, it means 'A person is a person through other people', thus capturing one of its core features – connectedness through others and communities. However, this does not even nearly capture everything it means. *Ubuntu* also implies compassion, respect, humanity, sympathy, and importantly, *doing* (for others). Accordingly, definitions of *ubuntu* vary, perhaps reflective of the depth and richness of what is meant by *ubuntu*. For the interested reader, Hailey (2008) provides an overview of the meaning of *ubuntu*.

Previous work in healthcare settings that incorporates the principles of *ubuntu* is unfortunately very sparse. However, a handful of studies, papers and books have explored the philosophy of *ubuntu* in relation to healthcare, psychology and therapeutic work with clients. For example, Edwards, Makunga, Ngcobo and Dhlomo (2004), through their experiences working in South Africa, have acknowledged the *ubuntu* knowledge system as an important, novel way of promoting mental health given its rich humanness and universally applicable principles. In recent times, there has also been a call to depart from the more Western-based approaches within psychology and psychotherapeutic practice that can sometimes perhaps be culturally biased and inappropriate. Here, Hanks (2008) argues, from a humanistic psychology perspective, that treatment and therapy needs to break away from traditionally ethnocentric and individually based paradigms, and move towards incorporating *ubuntu* as a way of promoting the key understanding of the self in relation to others. Other work, such as that of for example Roger Brooke, (year) also highlights Western-based dominance. Brooke (2008) identifies how Jungian theory enforces the focus on the individuation process, separateness and withdrawal of projections, and views groups as a threat to the process of individuation – this is in stark contrast to the core values of *ubuntu*.

Ubuntu emphasises connectedness with others. In a qualitative study, Bohman, van Wyk and Ekman (2011) looked at the personal experiences of care of 16 older adults in South Africa and identified the themes of focus on others, as well as participants' reflections on life. *Ubuntu*-centred therapy is beginning to be discussed in the context of therapeutic practice as a viable way of addressing patients' illness, and an opportunity to depart from Western-dominated therapeutic perspectives. Nefale and Van Dyk (2003) advocate for *ubuntu therapy* to be added to the psychotherapeutic framework as a way of offering effective treatment to the people of Africa, while breaking away from the traditional, Western-based models of therapy and disease. This approach will allow for the importance of culture on self-definition and mental health to be acknowledged with therapeutic practice (Nefale & Van Dyk, 2003). Van Dyk and Matoane (2010) highlight how *ubuntu therapy* may be effectively used to help families that are affected by HIV/AIDS in Africa. More recently, Marston (2015) reported on how the values of *ubuntu* can help facilitate social connectedness in the care of terminally ill children. With regard to *ubuntu* in brain injury care and rehabilitation, the literature is very limited. Nevertheless, Mokhosi and Griewe (2004) in their interesting study of 22 persons with traumatic brain injury and their relatives, report that cultural factors colour peoples' perception of the injury, but that families often stuck together long-term in the spirit of social cohesion that is so fundamental to *ubuntu*.

An example of hospital-based practice incorporating *ubuntu*

Could the principles of *ubuntu* also be more broadly or systemically utilised within brain-injury rehabilitation systems, as opposed to the individual psychotherapy practice described in the case of Mr M? The following vignette from the fourth author's (KS) occupational therapy practice illustrates how some of the core principles of *ubuntu* could be incorporated into hospital-based clinical practice, as well as its potential for wider systemic benefits. The following served as a stimulus for a small hospital-based project. Mirroring the broad principles of *ubuntu*, Mandela Day is celebrated in South Africa every year on Nelson Mandela's birthday on the 18th of July. The idea underpinning the celebration is for people to offer 67 minutes of their time in an act of service, and in this way to acknowledge the 67 years of Mandela's life that he sacrificed for achieving social justice in South Africa.

Life Esidemeni Intermediate Care, where the fourth author (KS) is employed, is a public/private partnership hospital providing rehabilitation, palliative and wound care services within the greater Cape Town area to the Department of Health in South Africa. Most of the clients admitted for rehabilitation at the hospital have suffered a moderate to severe cerebral vascular accident (stroke) or a traumatic brain injury. A six-week inpatient rehabilitation programme is offered to clients. Typically, each year a hospital would be the beneficiary of someone's 67 minutes of contributing the lives of others during Mandela Day. However, during 2013 the clinical team felt that their clients needed to be involved more actively and directly in the celebrations. It was thought this could be achieved on this occasion by clients giving their 67 minutes of service to feel a part of the fabric of society, to feel useful and to participate in meaningful and purposeful activity on the day. Ultimately, the team felt they needed to give their clients the opportunity to give to others. It was hoped that this would capture the essence of *ubuntu*.

From a practical point of view, the clinical team needed to come up with ideas in a very short space of time that were possible to implement and that their clients could actively participate in. The making of soup for a local crèche involved known logistical problems. It was therefore decided to make soup for the clients' visitors and friends when they visited in the afternoon. Most families have to travel far on public transport or by foot to reach the hospital, which adds significantly to their already profound financial burdens. Donations of vegetables were collected from a local farm and each hospital ward made a pot of soup. All clients who were able to sit up and actively participate were involved in cleaning and chopping vegetables. Many clients were only able to use one hand because of their hemiplegia. This was an opportunity to practise using occupational therapy assistive devices, dominance retraining, as well as preparation for eventual discharge into the community. At visiting time, tables were set up in the ward and manned by the clients who assumed responsibility for the dishing up and presenting of hot soup and bread to visiting families. This resulted in a positive experience for both the family members and clients, whose efforts and sacrifices were noted and appreciated. It was also an opportunity provided to clients to connect with and thank their relatives for their support and care.

Integrating *Ubuntu* into Existing Western Neuro-rehabilitation Models

What then would be the rationale, and per implication, evidence-base, behind considering a philosophy or value system contained within *ubuntu*, when thinking about neuro-rehabilitation service development and delivery? If service planners and commissioners were to start with the core assumptions of *ubuntu* when developing new rehabilitation services, current trends in client-centred care would necessarily then

have to also include the relational dimension as an important focus for outcome attainment. That is, to assist clients participating in rehabilitation to return to their human essence in the *ubuntu*-view is to support them to be *I am because we are*. Even if a service did not have the explicit remit to support the needs of significant others, they could not achieve the aim of enhancing psychological outcomes for the survivor unless the relationships with others, including family and the wider community, were incorporated as key foci of rehabilitation.

Some of the existing literature does provide an evidence-base for the value of a relationship-focus in neuro-rehabilitation outcomes. For example, the rehabilitation outcome of adult survivors of brain injury was predicted by child-relative adjustment (Sander et al., 2002), and so it follows that child-relative support such as that described by Daisley and Webster (2008) should enhance the outcome of the injured-parent. To return to the therapeutic relationship and clinician experience, the work of Michael Schonberger and colleagues has demonstrated the predictive value of the therapeutic working alliance for a range of client outcomes (Schonberger et al, 2006a, b). A recent study has highlighted that some post-injury sequelae for survivors can challenge the therapeutic working alliance (Yeates & Schonberger, 2015), and so deplete the very resource available to support survivor outcome and survivors' ability to negotiate other significant relationships in their social worlds. Supporting and enhancing the '*we are*' of the client and their therapist, and in turn also the client and their significant others, is an *Ubuntu*-informed approach to enhancing the personhood and self-identity of the client.

An indirect validation of the *ubuntu* concept also comes from neuroscience itself. In the contemporary emergence of social and affective neuroscience, the capacity of one brain to decode the social signals, intentions and minds of others, has attracted significant scientific interest (Lieberman, 2007). This includes work that looks at the unique qualities of interpersonal field and communication between people that emerge from the joint operation of specific neuro-anatomical circuits in two or more brains, in unison. An example is Gallese's (1999) contrast of perspectival and we-centric intersubjective space. The concept of 'intersubjective' holds on to the subjective experience of an individual, but to that which is emergent from their interactions with others – a dimension that can probably never be fully parsed out of the scientific study of the human, despite certain Western cultural trends. To underline this, Damasio's (1994; 2003) neurobiological perspective on consciousness emphasises how background feeling states and continuity of core self-experience emerge from embodiment, from constant interoceptive signals from the viscera. However, these signals are centrally about changing microstates in the body, primarily in response to external objects, notably other people. Thus self, body and social contact with others are inseparable. *I am because we are*, with the quality of the latter influencing the wellbeing of the former.

It follows from these arguments that *ubuntu*-focused rehabilitation does not partition the self and needs of the survivor from significant others (Yeates, 2007). It would invite those others into conversations and experience occurring under the roof of the clinical service, or even extend that service to undertake its core business within multiple locations within the community of the survivor. Given the importance of relationships to the make-up and wellbeing of the survivor, group psychotherapy, family and couples work, community initiatives and vocational rehabilitation with a focus on relationships within the workplace would all become the core business of rehabilitation, not specialist exceptions. However, some caution is necessary. One consideration, for example, might be that, because of the dominant individualist constructions of personhood in Western society, survivors of brain injury in these societies may not find an *ubuntu*-focus in their rehabilitation to be meaningful or even helpful.

Some clients may choose not to participate in couples, family or group work, because they perceive a need to work on their problems themselves. Alternatively, a client may access help from others, either in the clinic or in the community, and rather than feel empowered by acting within a collective or network, instead feel disempowered because they had to rely on others. Clients may value a sense of mastery by achieving their goals through actions as an autonomous individual, as they may have done pre-injury. Proponents of relational perspectives such as *ubuntu* must therefore sensitively navigate the tensions between potential benefit from these new ideas, and a clash of values between these and pre-existing individualist discourses organising both services and survivors themselves.

Conclusion

Ubuntu is clearly a complex, multi-faceted concept. Nevertheless, one of its core aspects is similar to compassion. It is, however, a unique type of compassion, as it essentially relates to compassion for the wider group, through activity and doing. It is about collectivism, as opposed to individualism. In many Western cultures individualism is often rewarded and seen as desirable for ensuring personal success. However, in some situations individualism may not produce the long-term success necessary for good social outcomes. In this regard it is important to keep in mind that acquired brain injury does not have a 'cure'. Nevertheless, not abandoning hope is also important, and *ubuntu* indirectly facilitates the preservation of hope through its emphasis on humanity and collectivism (Coetzer, 2017). Accordingly, many contemporaneous approaches to neurorehabilitation would acknowledge this through work beyond the 'index patient', as well as the acute phase. For this reason, *ubuntu* may have the potential to further shape some of the clinical values underpinning how we think about the lives of people long after their period of active brain-injury rehabilitation has ceased. Ultimately, clients live their lives within their families, communities, and relationships with others within broader society.

The formal delivery of healthcare may well end at the hospital and community clinics, but our responsibility ultimately extends longer-term, and in particular, to society. Kwizera and Iputo (2011) remind us that *ubuntu* emphasises our humaneness, likening this to a social responsibility, and urge that these are concepts that should be integrated into healthcare education. The collectivism central to Ubuntu lends itself to research endeavours intended to be beneficial to the group, or wider society (Balchin et al, 2017). It is hoped that future educational and academic work might explore how some of the principles of *ubuntu* could be incorporated into, for example, goal planning for post-rehabilitation outcomes, or even the use of healthcare through educational initiatives. While an individual might become more compassionate towards the good of others in the context of their own suffering, by including the family, community or immediate 'team' there may also be wider organisational and societal implications. Through the principles of *ubuntu* one interesting and potentially wider implication for the users and providers of healthcare may be that 'our health and social care systems could become what they are because of who we all are'.

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